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Palliative care for people with dementia living at home: A systematic review of interventions

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Abstract

Background: The European Association for Palliative Care White Paper defined optimal palliative care in dementia based on evidence and expert consensus. Yet, we know little on how to achieve this for people with dementia living and dying at home.

Aims: To examine evidence on home palliative care interventions in dementia, in terms of their effectiveness on end-of-life care outcomes, factors influencing implementation, the extent to which they address the European Association for Palliative Care palliative care domains and evidence gaps.

Design: A systematic review of home palliative care interventions in dementia.

Data sources: The review adhered to the PRISMA guidelines and the protocol was registered with PROSPERO (CRD42018093607). We searched four electronic databases up to April 2018 (PubMed, Scopus, Cochrane library and CINAHL) and conducted lateral searches.

Results: We retrieved eight relevant studies, none of which was of high quality. The evidence, albeit of generally weak quality, showed the potential benefits of the interventions in improving end-of-life care outcomes, for example, behavioural disturbances. The interventions most commonly focused on optimal symptom management, continuity of care and psychosocial support. Other European Association for Palliative Care domains identified as important in palliative care for people with dementia, for example, prognostication of dying or avoidance of burdensome interventions were under-reported. No direct evidence on facilitators and barriers to implementation was found.

Conclusions: The review highlights the paucity of high-quality dementia-specific research in this area and recommends key areas for future work, for example, the need for process evaluation to identify facilitators and barriers to implementing interventions.

Keywords

Palliative care, terminal care, dementia, home care services, primary, health care

What is already known about the topic?

- There is an urgent need to find effective strategies to improve home-based care for people with dementia.
- The European Association for Palliative Care (EAPC) White Paper defined optimal palliative care in dementia based on evidence and expert consensus.
- We know little about the evidence base on how to achieve optimal palliative care in dementia for people living and dying at home.

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What this paper adds?

- There is evidence, albeit limited and of generally weak quality, that shows the potential benefits of home palliative care interventions in dementia in improving end-of-life care outcomes, such as the management and reduction of behavioural disturbances in people with dementia.
- The interventions focused mainly on symptom management, continuity of care and psychosocial support, with less attention paid to four other EAPC domains considered important for people with dementia, for example, prognostication of dying or avoidance of burdensome interventions.
- The paper highlights several gaps in the evidence, including the limited evidence on facilitators and barriers to implementing the intervention and the lack of consensus on outcome measures used.

Implications for practice and research

- The EAPC's definition of optimal palliative care in dementia provided a useful framework for a systematic assessment of the range and focus of evidence of what is effective for people with dementia living and dying at home.
- The review highlights the paucity of high-quality dementia-specific research in this area and recommends key areas for future work, such as the need for process evaluations to identify facilitators and barriers to implementing interventions or for a standard outcome set to facilitate comparisons and meta-analyses.
- High-quality dementia-specific research is required to further support the evidence base for palliative care interventions to be a routine care for people with dementia living and dying at home.

Background

Dementia is a life-limiting illness characterised by widespread physical, cognitive and behavioural impairment, resulting in severe disabilities that persist until death.[1,2] The global prevalence of dementia is projected to increase to almost 132 million by 2050.[3] The high demand for dementia care, the individual's preference to stay at home for as long as possible combined with limited supply and rising costs of institutional long-term care services highlight an urgent need to find effective strategies to improve home-based care for people with dementia, including those with advanced dementia requiring end-of-life care.[4–7]

To improve the quality of life of people with dementia and their families, a palliative care approach has been widely recommended.[8–10] In 2014, van der Steen and colleagues published the European Association for Palliative Care (EAPC) White Paper defining optimal palliative care in dementia based on evidence and expert consensus. These experts achieved consensus on 57 salient recommendations that fall under 11 important domains of palliative care: applicability of palliative care; person-centred care, communication, and shared-decision making; setting care goals and advance planning; continuity of care; prognostication and timely recognition of dying; avoiding overly aggressive, burdensome or futile treatment; optimal treatment of symptoms and providing comfort; psychosocial and spiritual support; family care and involvement; education of the health care team; and societal and ethical issues (Supplementary file 1).[11] The majority of this evidence draws on work in long-term care and institutional settings. Less well known is the evidence on the effectiveness of palliative care interventions for people with dementia living at home.

A Cochrane review on palliative care interventions in advanced dementia found only two low-quality studies, neither of which was conducted in the home setting.[12] In a systematic review that aimed to identify populations appropriate for palliative care and effective palliative care models, they found improvements in pain and depressive symptoms in people with dementia. However, this study did not indicate whether the population with dementia was living at home.[13] Another Cochrane review evaluated palliative care services for people living at home with advanced incurable illnesses, including those with dementia. They found reliable evidence that these services could reduce symptom burden and increase the chance that people with terminal diseases will die at home. However, the evaluated services were only for people with cancer and organ failure, rather than for people with dementia.[14]

In the last 5 years, there have been an increasing policy commitment to improving dementia care with concomitant increase in research funding.[15,16] In order to guide efforts to improve the care for people with dementia living and dying at home, we conducted a systematic review to examine evidence on palliative care interventions for this population. Our overall aim was to synthesise evidence on the effectiveness of palliative care interventions on end-of-life care outcomes (e.g. patient death at home or pain) for people with dementia living at home. In addition, we reviewed facilitators and barriers to implementing these interventions, assessed the extent to which the interventions reflected optimal palliative care in dementia as defined in the EAPC White Paper and identified gaps in evidence.

Methods

Design

The systematic review adhered to the PRISMA guidelines, and the protocol was registered with the PROSPERO

international prospective register of systematic reviews (www.crd.york.ac.uk/prospero/-CRD42018093607). The PRISMA Checklist is available in Supplementary file 2.

Eligibility criteria

We included peer-reviewed quantitative studies evaluating palliative care interventions for people with any type of dementia living at home. This included randomised controlled trials (RCTs), controlled clinical trials (CCTs), non-randomised controlled studies, controlled and uncontrolled before and after studies, interrupted time series (ITSs) and case studies published in either English or Dutch. To provide a comprehensive overview of existing research in this area, we included specialist palliative care services and non-specialist palliative care interventions, that is, interventions that were not labelled as 'palliative care' but described as aiming to improve care at the end of life for people with dementia.

Specialist palliative care included services with the following four elements: (1) designed primarily for people with dementia living at home, (2) aim to support people outside hospital and other institutional settings for as long as possible and to enable people to stay at home, (3) be provided by specialists in palliative care or intermediate palliative/hospice care, and (4) provide comprehensive care addressing different physical and psychosocial components of palliative care.[14] Non-specialist palliative care included interventions that focused either on people with advanced/severe/late-stage dementia living at home or on people with dementia living at home with the potential impact on palliative care or death and dying or end-of-life care outcomes.

End-of-life care outcomes included patient death at home as the primary outcome. Secondary outcomes included time the patient spent at home, pain, dyspnoea, depressive symptoms, behavioural symptoms common at the end of life, existential or spiritual concerns, communication or care planning, experience or satisfaction, functional status, health-related quality of life, and resource use.[14] In addition to the outcomes registered in Prospero, we added institutionalisation as a secondary outcome, as it had been reported in two of the studies included. Studies that did not focus entirely on the home setting or dementia (e.g. studies on primary care or advanced incurable illnesses) were also included, provided that the majority of the participants ($>$50%) lived at home or had dementia.

Search strategy

The search strategy was undertaken in two phases from April to June 2018 to search for literature relating to specialist palliative care services (Phase 1) and non-specialist palliative care interventions (Phase 2). Two search strategies were developed by the research team with advice from an information specialist. In Phase 1, we used a combination of MESH headings, controlled vocabulary and free-text terms to cover palliative/end-of-life/terminal care, dementia, and the home setting. In Phase 2, we covered the home setting combined with either advanced/severe/late-stage dementia or dementia with outcome measures relating to palliative care or death or dying. We searched four electronic databases: PubMed, Scopus, Cochrane Library, including the Cochrane Central Register of Controlled Trials (CENTRAL) and Cochrane Database of Systematic Reviews, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) (from inception to April 2018). The search strategies were validated in PubMed and translated for use in the other databases (Table 1). We also performed hand-searching of relevant journals and reference lists of included and relevant articles and citation tracking in Google Scholar). We also contacted the author of a relevant study protocol to ask for update about their study.[17]

Study selection

The first author (R.M.) removed duplicates and screened the titles and abstracts for relevance. Studies considered potentially relevant were marked as 'include' or 'uncertain'. A random 20% of articles were independently screened by two co-authors (F.B. and J.L.). Full texts were retrieved for studies deemed as 'included' or 'uncertain'. These were screened by R.M. against the eligibility criteria and checked by F.B. and J.L. Discrepancies were discussed and resolved among the three authors. A PRISMA flowchart was created to describe the selection procedure and the rationale for exclusion was compiled. Mendeley citation management software was used for deduplication and management of references. Multiple reports about a similar study were collated to ensure that each study rather than each paper is the unit of interest.

Data extraction

The data were extracted to a specially designed form in MS Excel version 16 (© Microsoft 2018). This form was pilot-tested on three articles to ensure consistency and was approved by the research team. Characteristics of the included studies were extracted by R.M. and checked for accuracy by F.B. Study characteristics included country, study design, data collection method, research question (aim), setting, participants and intervention type. R.M. and F.B. independently extracted data on outcomes. Discrepancies were resolved by discussion and consensus between three reviewers (R.M., F.B., J.L.). Qualitative data on intervention components and potential barriers and facilitators to implementing the interventions were also extracted.

Table 1. Search syntax for the database search.

Phase 1. Specialist palliative care services	
PubMed	(((((((‘Palliative care’(MESH)) OR palliative care(Title/Abstract) OR ‘Terminal care’(MESH) OR terminal care(Title/Abstract) OR end of life care(Title/Abstract) AND (((‘Dementia’(MESH) OR dementia(Title/Abstract) OR Alzheimer(Title/Abstract) AND ((((home(Title/Abstract) OR ‘Primary health care’ (MESH) OR ‘General practice’(MESH) OR community(Title/Abstract)
Scopus	(palliative care OR terminal care OR end of life care) AND (dementia OR Alzheimer) AND (community OR home)
CINAHL	((MH ‘Palliative Care’) OR ‘palliative care’ OR terminal care OR end of life care) AND ((MH ‘Primary Health Care’) OR ‘primary health care’ (MH ‘Family Practice’) OR ‘general practice’ OR community OR home) AND ((MH ‘Dementia’) OR ‘dementia’ OR Alzheimer)
Cochrane library	‘Palliative care’ and ‘dementia’ and home
Phase 2. Non-specialist palliative care interventions	
PubMed	(((((((Dementia[MeSH Terms)) OR dementia(Title/Abstract) OR Alzheimer(Title/Abstract) AND (((((Home health nursing(MeSH Terms)) OR Primary health care(MeSH Terms)) OR General practice(MeSH Terms)) OR home(Title/Abstract) OR community(Title/Abstract) AND (((((Death(Title/Abstract) OR Die(Title/Abstract) OR Dying(Title/Abstract) OR Deceased(Title/Abstract) OR ‘end of life’(Title/Abstract) OR (((((((Advanced(Title/Abstract) OR Severe(Title/Abstract) OR ‘Late stage’(Title/Abstract) OR ‘Late-stage’(Title/Abstract) AND (((Dementia(MeSH Terms)) OR dementia(Title/Abstract) OR Alzheimer(Title/Abstract) AND (((((Home health nursing(MeSH Terms)) OR Primary health care(MeSH Terms)) OR General practice(MeSH Terms)) OR home(Title/Abstract) OR community(Title/Abstract)
Scopus	(KEY (*dementia* OR *alzheimer*) AND KEY (‘*Primary care’* OR ‘*General practice’* OR *community* OR *home* OR ‘*Primary health care’)* AND TITLE-ABS-KEY (*advanced* OR *severe* OR ‘*late stage’* OR ‘*late-stage’)* OR TITLE-ABS-KEY (*death* OR *dying* OR *die* OR *deceased*))
CINAHL	((MH ‘Dementia’) OR ‘dementia’ OR alzheimers) AND ((MH ‘Primary Health Care’) OR ‘primary health care’ OR (MH ‘Family Practice’) OR ‘general practice’ OR community OR home) AND ((Advanced OR severe OR ‘Late stage’ OR ‘Late-stage’) OR (Death OR Dying OR die OR deceased))
Cochrane library	((Advanced OR Severe OR ‘Late Stage’) OR (Death OR Dying OR Die OR Deceased)) AND (Dementia OR ‘dementia’ OR Alzheimer) AND home

Quality appraisal

Quality appraisal was conducted by R.M. and F.B. using the ‘Quality Assessment Tool for Quantitative Studies’ developed by Effective Public Health Practice Project.[18] Studies were rated as either strong, moderate or weak on the following components: selection bias, study design, confounders, blinding, data collection methods, withdrawals/dropouts, intervention integrity, and appropriate data analyses used. Two authors discussed any discrepancies and reached consensus. The quality was considered as either strong (no weak ratings), moderate (one weak rating), or weak (two or more weak ratings).

Data synthesis

We described the included studies in terms of country of origin, design, data collection method, intervention components and participants. Due to heterogeneity in interventions and outcomes, data were not pooled in a meta-analysis. Instead, the outcomes of the interventions were presented separately in a table with an indication of whether the effects of the intervention were positive, negative or statistically insignificant. The available data did not allow us to calculate effect sizes. Hence, we presented data in the way it was reported in the study (e.g. P values). Qualitative data on facilitators and barriers were synthesised thematically and presented in a narrative way. We mapped the components of each of the interventions according to the 11 EAPC White Paper domains. This ensured that data synthesis was focused on aspects of care identified by international experts as important in palliative care for people with dementia. This provided insights on potential gaps and room for improvement that could better inform developers of home palliative care interventions in dementia. No subgroup analysis was conducted to look at the difference between specialist palliative care services and non-specialist palliative care interventions due to low number of articles relating to specialist palliative care.

Results

In all, three articles met the inclusion criteria for specialist palliative care services and six for non-specialist palliative care interventions. The overview of the study selection is depicted in Figure 1.

General overview of the studies

We identified three studies evaluating specialist palliative care services[19–21] and five evaluating non-specialist

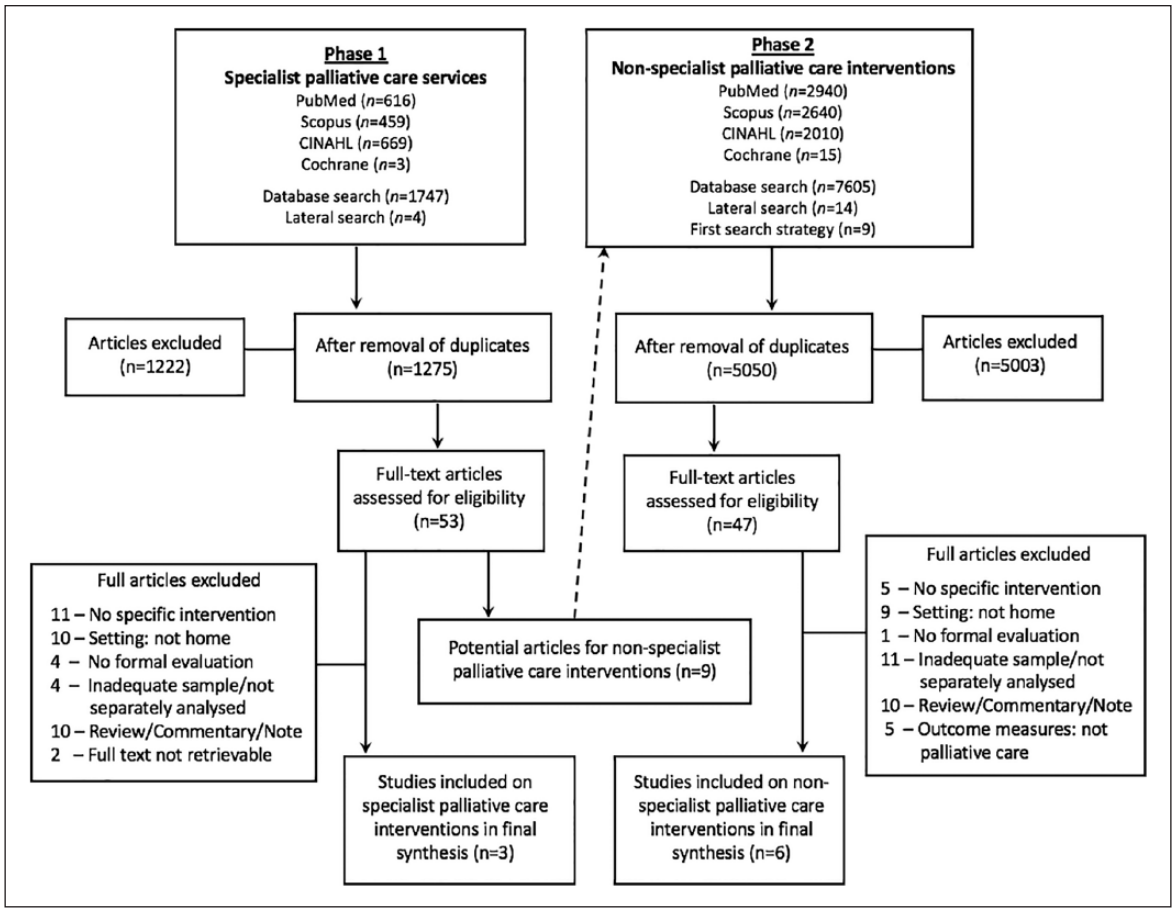

Figure 1. PRISMA flowchart of selection process.

palliative care interventions (Table 2).[22–27] One study on non-specialist palliative care intervention was reported in two articles.[22,23] Four of the studies presented evidence from the United States,[19,20,24,25] two from Italy,[22,23,27] and one each from the United Kingdom[26] and Japan.[21] Of the studies, four were RCTs,[21–24] two retrospective case-control studies,[19,25] one retrospective cross-sectional study[20] and one with an unclear study design.[27] All studies used quantitative methods, one of which also used qualitative methods.[20] All studies included both male and female participants, with the majority in their 80s and women. Seven studies included people with dementia and one included terminally ill participants, 64% of whom had dementia.[20] All interventions aimed to improve end-of-life care for people with dementia living at home, while one offered additional support to family caregivers.[24]

Quality of the evidence

Overall, five of the eight studies were considered of weak quality, particularly due to high risk for selection bias, inability to achieve blinding and inability to clearly measure and/or report the integrity and consistency of the intervention (Table 2).[19,20,22,23,25,27] Of these studies, three did not control for confounders and used inappropriate data analysis techniques,[20,22,23,27] while the other two studies took potential confounders into account by using propensity score matching to identify control group and analysed the data appropriately.[19,25] These five studies received moderate ratings for using health/medical records as the source of data, but the procedures for data collection were inadequately reported.

The three other studies were assessed as being of moderate quality, two received a weak rating for not achieving blinding,[21,26] while the other one received a weak rating for selection bias due to a small sample size.[24] These studies received strong ratings for study design, confounders, data collection, withdrawals/drop-outs, intervention integrity, and the data analysis techniques used. The quality of the qualitative data from the mixed-methods study was not assessed, as these data were used solely to identify potential barriers and facilitators to implementing the intervention.[20] (See Supplementary file 3 for the composite component ratings for each study).

Table 2. General overview of the included studies on palliative care interventions ($n = 8$).

Studies evaluating specialist palliative care services ($n = 3$)

Study	Study design	Specialist palliative care services	Study participants	Quality[a]
Cassel 2016 United States of America	Observational retrospective (case-control) Quantitative	**Transitions programme** – developed to improve palliative care for home-bound individuals with advanced chronic illness, including those with dementia. - Focused on training a specialty palliative care team comprising of doctors, nurses, spiritual care providers, and social workers. Specific interventions included in-home medical consultation, prognostication of further survival, caregiver support and advance care planning, pain and non-pain symptom management, education to promote awareness of illness trajectory and treatment choices, and psychosocial and spiritual support. - Delivered through home visits (frequency of home visits per week: 4–6 times from the registered nurses, 1–3 times from the social workers, and from the Chaplain services if needed). - When identified goals have been achieved, patients continued to receive home visits, although less frequently, supplemented with scheduled telephone calls for case management to ensure continuity of care.	Home-bound people with Medicare Advantage insurance, 2 years usage data, and dementia. (case group, n = 92; control group identified using propensity score matching, n = 276).	**Weak**
Holley 2009 United States of America	Observational retrospective study (cross-sectional) Mixed-method	**Palliative Access Through Care at Home (PATCH)** – developed to improve palliative care for vulnerable home-bound older adults with limited access to medical care, of which the majority had dementia. - Focused on training medical staff to improve a patient's quality of life, symptom management, reducing polypharmacy, supporting caregivers and assisting with advance medical planning, complex decision-making and facilitating the transitions of care. Specific interventions included medical interventions, home assessment, communication and goals of care and availability of care. - Delivered through home visits (frequency per week: 4 half-days or based on patients' needs from weekly to every 3 months) and 24 hour access to a member of the care team by telephone and on-call paging system.	**Chart review:** Home-bound people enrolled in Medicare Advantage Part B, had an existing University of Chicago affiliation, had limited life-expectancy based on primary caregiver's perception (>65 years old; 64% of the sample had dementia), n = 74. **Telephone interviews:** n = 22. **Face-to-face in-depth interviews:** n = 13: primary caregivers.	**Weak**
Nakanishi 2018 Japan	Randomised controlled trial Quantitative	**Behaviour Analytics and Support Enhancement (BASE) programme** – developed as a palliative care-based psychosocial intervention to explore unmet needs and address challenging behaviours of home-bound people with dementia. - Focused on a 2-day training course for care professionals from local home care service providers to identify and manage unmet needs in order to reduce challenging behaviours of people with dementia. The topics addressed in the training included dementia as an illness, challenging behaviour as a communication of unmet needs, assessment of challenging behaviour and exploration of unmet needs and action plans. The training course was based on the Behavioural and Psychological Symptoms of Dementia Programme of Care, which is based on the well-developed national guidelines for dementia care. - Delivered through home visits. The care professionals also conducted ongoing assessment of challenging behaviour, multiagency discussion meetings to ensure continuity of care, monthly multiagency discussion and care managers-scheduled mandatory monthly meetings.	Home-bound patients with a diagnosis of dementia (>65 years old) of participating care professionals (intervention group, n = 141; control group, n = 142).	**Moderate**

Table 2. (Continued)

Studies evaluating non-specialist palliative care interventions ($n = 5$)

Study	Study design	Non-specialist palliative care interventions	Study participants	Quality[a]
Baker 2001 United Kingdom	Randomised controlled trial Quantitative	**Multi-Sensory Stimulation (MSS) –** developed to improve behaviour and mood of older adults with moderate to severe dementia by exploring stimuli and being in a state of relaxation. MSS was added to a credible control condition of eight standardised Activity sessions. The MSS and Activity sessions had similar non-specific conditions: one-to-one attention, staff time, and number, length, frequency, location and time of sessions. - Focused on stimulating all senses, except taste, using multisensory experience, unpatterned non-sequential stimuli, nondirective enabling approach by staff and no intellectual/physical demand. - Delivered by a trained therapist at two day-centres fully equipped with MSS rooms and another room equipped with multi-sensory environments.	Home-bound people with moderate-severe dementia with a primary carer; referred to the Elderly Mental Health Service of Dorset HealthCare NHS Trust by their general practitioner, who attended at the participating day-centres for 2 or more days/week; had no other psychiatric diagnoses; and had not received more than 1 MSS session in the last 3 months. (intervention group, n = 25; control group, n = 25)	**Moderate**
Reisberg 2017 United States of America	Randomised controlled trial Quantitative	**Comprehensive, Individualised, Person-Centred Management (CI-PCM)** – developed to complement memantine treatment in reducing behavioural disturbance among community-dwelling people with moderate to severe Alzheimer's disease. - Focused on training the primary caregivers of people with dementia to deliver care based on the universal human treatment and human rights principles, which encompassed the majority of the palliative care domains. - Delivered in New York University Langone Medical Centre.	People with dementia of the Alzheimer type, who resided at the community at the time of screening, and had a family and/or professional caregiver willing and able to participate in the study. (intervention group, n = 10; control group, n = 10)	**Moderate**
Wilson 2015 United States	Observational retrospective (case-control) Quantitative	**House Calls** – developed to provide medical care to home-bound frail older people including those with Alzheimer's disease and dementia - Focused on ensuring continuity of care, integrated care based on patients' needs, coordinated team-based approaches to medical care and social work. - Delivered by a team of physicians, nurse practitioners, non-clinical care managers and social workers.	Home-bound people with Medicare Advantage insurance enrolled in the House Calls programme during the study period (2004–2006). (case group, n = 144; control group identified using propensity score matching, n = 440).	**Weak**
Aimonino 2001 Italy	Unclear[b] Quantitative	**Home Hospitalisation Service (HHS) –** developed to perform medical interventions, which are usually done in hospital, at home of people with severe dementia. - Intervention components and implementation unclear.	Patients with advanced dementia admitted in hospital (intervention group, n = 41; control group, n = 41)	**Weak**
Fabris 2004 and Tibaldi 2004 Italy	Randomised controlled trial Quantitative	**Home Hospitalisation Service (HHS) –** same intervention evaluated by Aimonino et al 2001 - Focused on bringing all critical elements of hospital care to the home setting of acutely ill patient, such as equipped physician and nursing care working together, medicines and appropriate diagnostic and therapeutic technologies. - Delivered by geriatricians, nurses, physiotherapists, social workers and counsellors. The HHS is operative for 7 days during the week, starting at eight o'clock in the morning and ends at eight p.m. and there is a daily meeting for planning care management of each subject to ensure the coordination and continued provision of care.	Patients with advanced dementia admitted in hospital due to acute illness, were stable, not expected to require emergency interventions, with appropriate care supervision, had telephone connection and resided in the hospital catchment area. (intervention group, n = 56; control group, n = 53)	**Weak**

[a]Overall quality was considered as either strong (no weak ratings), moderate (one weak rating), or weak (two or more weak ratings) based on the rating of the integrity of each of the following components: selection bias, confounders, blinding, data collection methods, withdrawals/ dropouts, intervention integrity, and appropriate data analyses used.
[b]Study design is deemed unclear due to the inadequate information provided about the implementation of the study, in particular about randomisation of participants.

Palliative care interventions for people with dementia living at home

Overview of specialist palliative care services. We identified three specialist palliative care services, all of which focused on educating the multi-disciplinary healthcare team (Table 2).[19–21] Transitions programme[19] and Palliative Access Through Care at Home (PATCH)[20] were specialist palliative care services delivered by trained specialist palliative care team comprising typically of geriatricians, nurses and social workers. Behaviour Analytics & Support Enhancement (BASE) is a palliative care-based psychosocial intervention delivered by trained professional home care providers, who aimed to explore unmet needs and address challenging behaviours of people with dementia in coordination with a multidisciplinary healthcare team.[21] These interventions were delivered through home visits, ranging from four to six times per week or based on patients' needs. Each intervention had multiple components, such as symptom management, medical consultation, reduction of polypharmacy, assistance with advance care planning and transitions of care, and psychosocial and spiritual support.

Overview of non-specialist palliative care interventions. Non-specialist palliative care encompassed a diverse range of interventions for people with advanced dementia (Table 2). Two studies aimed to address behavioural disturbances, one by using multi-sensory stimulation (MSS) provided in day-care centres[26] and one by training and supporting primary caregivers, that is, formal or family caregiver, to use the Comprehensive, Individualised, Person-Centred Management (CI-PCM) approach.[24] The other three studies aimed to bring care that is usually offered in institutions or hospitals to patients' homes. One of these studies evaluated the medical care offered by House Calls[25] and two evaluated the diagnostic and therapeutic treatments for acute illnesses offered by Home Hospitalisation Service.[22,23,27]

Outcomes of home palliative care interventions in dementia. The outcomes of home palliative care interventions for people with dementia are summarised in Table 3.

Patient death at home. One of the studies (retrospective cross-sectional study of weak quality) reported outcome on patient death at home.[20] This study showed that about two thirds of deceased participants with dementia who received palliative care from the trained specialist care team died at home and inpatient hospice. However, this evidence on effectiveness was inconclusive, as it relied exclusively on cross-sectional data collected through chart review and thus there was no control group or before and after data.

Institutionalisation. Two of the studies reported outcome on institutionalisation. These studies (one RCT and one unclear study design, both studies of weak quality) evaluated Home Hospitalisation Service.[22,27] They suggested that people with advanced dementia who received diagnostic and acute care at their own homes were less likely to be transferred to nursing homes and more likely to stay at home.

Functional status. One of the studies (RCT of moderate quality) evaluated functional status as an outcome.[24] This study showed that the functional status of people with dementia who received care from the trained primary caregivers on CI-PCM approach were more likely to improve than those who did not at all follow-up measurements (months 4, 12 and 28).

Behavioural symptoms common at the end of life. Four of the studies assessed behavioural symptoms, all of which suggested that home palliative care interventions are more effective than usual care in reducing behavioural disturbances.[21,23,24,26] Three studies (all RCTs of moderate quality) suggested positive effects of home palliative care interventions on behavioural disturbances of people with dementia. These interventions included the MSS sessions offered in day-care centres[26] and the training courses on BASE for professional home care providers[21] and on CI-PCM approach for primary caregivers.[24] The fourth study (RCT of weak quality) reported marginally significant effect in the same direction on sleeping disorder, agitation/aggressiveness and feeding disorders.[23] However, evidence on the duration of effects was conflicting. One study found long-term positive effects of the training course on CI-PCM approach for primary caregivers on behavioural symptoms,[24] whereas another study found that behavioural symptoms deteriorated after the MSS sessions had ceased. This deterioration has been attributed to potential withdrawal effect from the one-to-one session and the appropriate stimulation.[26]

Pain. One of the studies (RCT of moderate quality) reported pain as an outcome, but results were inconclusive.[21] This study evaluated the training course on BASE, a palliative care-based psychosocial intervention offered to home care professionals who were responsible for assessing the pain of participants with dementia and discussing this assessment with the multidisciplinary team. This study suggested that compared with control group, the participants in the intervention group had significant pain reduction from baseline to follow-up assessment. However, after controlling for baseline characteristics at follow-up, no significant difference in pain was found between the two groups potentially due to the higher pain score in the intervention group at follow-up. This

Table 3. Outcomes of home palliative care interventions for people with dementia.

Primary outcome measure		
Patient death at home Holley 2009	**Based on chart-review of deceased PATCH participants**	
	• More than two thirds of patients died at home and inpatient hospice	45.5% (home) and 22.7% (inpatient hospice)
	• Almost a third died in hospital	27.3%
	• Low percentage of deceased patients died in a nursing home	4.5%
	Based on chart-review of deceased PATCH participants with dementia	
	• More than half of patients with dementia died at home and inpatient hospice	35.7% (home) and 28.6% (inpatient hospice)
	• More than a third of patients with dementia died in hospital	35.7%
	• No patient with dementia died in a nursing home	0%
Secondary outcome measures		
Institutionalisation Aimonino 2001	**Source of data unclear**	**HHS group vs. Control (GMW) group**
	• Mortality rates	7.3% vs. 2.4%, p-value=NS
	• Lower percentage of patients being transferred to nursing homes	2.4% vs. 41.46, p-value<0.001
	• Higher percentage of patients who stayed/returned at home	90.2% vs. 56.1%, p-value<0.001
Fabris 2004	**Source of data unclear**	**HHS group vs. Control (GMW) group**
	• Mortality rates	17.8% vs. 20.7%, p-value=NS
	• Length of stay	27.6% vs. 25.1%, p-value=NS
	• Percentage of patients transferred to nursing homes	3.6% vs.32.1%, p-value<0.001
	• Higher percentage of patients who stayed/returned at home	78.6% vs. 47.2%, p-value<0.001
Functional status Reisberg 2017	**Improvement in functional status** - Based on caregiver-rated Functional Assessment Staging Disability Score (FAST-DS), with higher scores indicating greater impairment	**CI-PCM group vs. control group**
	• Baseline (mean score)	6.6 vs. 6.6, p-value=NS
	• Week 4 (mean score)	6.5 vs. 6.6, p-value=<0.05
	• Week 12 (mean score)	6.3 vs. 6.6, p-value=<0.05
	• Week 28 (mean score)	6.2 vs. 6.8, p-value=<0.05
Behavioural symptoms Nakanishi 2018	**Reduction in challenging behaviours** - Based on care professional-rated Neuropsychiatric Inventory-Nursing Home version (NPI-NH). The score for each item ranges from 0-12, with higher scores indicating worse behaviour.	**BASE participants vs. Control group**
	• Mean score in challenging behaviour at baseline	18.3 vs. 11.6, p-value<0.001
	• Mean score in challenging behaviours after adjusting for baseline characteristics	6.88, p-value<0.001 vs. 0.95, p-value=0.346
Baker 2001	**Better immediate effects on behaviour and mood 10 minutes before and after the intervention** - Based on the ratings by day hospital staff using INTERACT short	**MSS group vs. control (Activity group)**
	• More spontaneous speech; Relating to people better; More attentive to/focused on the environment; Doing more from their own initiative; Enjoying themselves; More active or alert/less bored/inactive	Similar in both groups

(Continued)

Table 3. (Continued)

	Better immediate effects on behaviour and mood during the intervention - Based on keyworker-rated 22 items INTERACT that assesses relaxation, mood and speech	
	• Talked more spontaneously	2.03 vs. 2.68, p-value=0.04
	• Talked with normal length sentences	3.71 vs. 3.04, p-value=0.05
	• Recalled more memories	2.54 vs. 1.89, p-value=0.01
	Better outcomes on behaviour and mood after 4-8 sessions - based on ratings by day hospital staff using REHAB, a widely used rating form originally designed to assess change in long-stay psychiatric patients	
	• Rehab Speech Skills (amount of speech, initiation of speech)	No change vs. Improved
	• REHAB subscales: speech disturbance (sense clarity), self-care and general behaviour	No change vs. no change
	Better outcomes on behaviour and mood after 4-8 sessions - Based on ratings by carers and aided by a research assistant using Behaviour and Mood Disturbance Scale (BMD) scale (home)	Improved vs. Deteriorated
	Better outcomes on behaviour and mood after 4-8 sessions - based on Behaviour Rating Scale (BRS), a more formal tool to assess change in behaviour, such as constant talking, making false accusations and hoarding (home)	Improved vs. No change
	Deterioration in behavioural and mood – based on REHAB subscales: speech disturbance (sense clarity), self-care and general behaviour	Deteriorated vs. deteriorated
Reisberg 2017	**Improvement in behavioural symptoms at months 12 and 28** - Based on caregiver-rated Behavioural Pathology in Alzheimer's Disease Frequency-Weighted Severity Scale assessment tool, with higher scores indicating increased magnitude and frequency of behavioural disturbances	**CI-PCM group vs. control group**
	• Baseline (mean score)	25.1 vs. 21.6, p-value=NS
	• Week 4 (mean score)	≈16 vs. ≈17, p-value=NS
	• Week 12 (mean score)	11.7 vs. 19.6, p-value$<$0.05
	• Week 28 (mean score)	7.2 vs. 23.7, p-value$<$0.05
	Improvement in behavioural symptoms at month 28 - Based on caregiver-rated Revised Memory and Behaviour Problems checklist, with higher scores indicating increased more frequent behavioural problems	
	• Baseline (mean score)	29.9 vs. 32.7, p-value=NS
	• Week 4 (mean score)	≈31 vs. ≈30, p-value=NS
	• Week 12 (mean score)	≈24 vs. ≈32, p-value=NS
	• Week 28 (mean score)	23.8 vs. 34.9, p-value$<$0.05
Tibaldi 2004	**Reduction in behavioural disturbances** - Source of data unclear	**HHS group vs. Control (GMW) group**
	• Sleeping disorder	9% vs. 43.3%, p-value$<$0.001
	• Agitation/Aggressiveness	8.9% vs. 41.5%, p-value$<$0.001
	• Feeding disorders	8.9% vs. 39.6%, p-value$<$0.001

Table 3. (Continued)

Pain Nakanishi 2018	**Decline in pain from baseline to follow-up, but no difference in pain between the two groups after adjusting for baseline characteristics** - Based on care professional-rated Abbey Pain scale rated by the care professionals. An overall assessment of pain intensity ranges from 0-18, with higher scores indicating more pain intensity.	**BASE participants vs. Control group**
	• Mean score in pain intensity at baseline	2.4 vs. 1.0, p-value<0.001
	• Mean score in pain intensity at follow-up	1.8 vs. 0.9
	• Pain intensity at follow-up after adjusting for baseline characteristics	2.63, p-value=0.01 vs. 0.43, p-value=0.671
Satisfaction Holley 2009	**High satisfaction** - Based on telephone interviews with caregivers of deceased PATCH participants	
	• Extremely satisfied	72.7%
	• Very satisfied	18.2%
	• Satisfied	9.1%
	• Somewhat or not at all satisfied	0%
	High satisfaction - Based on telephone interviews with caregivers of deceased PATCH participants with dementia	
	• Extremely satisfied	64.3%
	• Very satisfied	21.4%
	• Satisfied	14.3%
	• Somewhat or not at all satisfied	0%
Resource use Cassel 2009	**Based on records from Sharp Administrative system**	**Transitions group vs. control group**
	Lower hospital, non-hospital and all costs	
	• Average hospital costs/month	$885 vs. 3574, p-value<0.001
	• Average non-hospital costs/month	649 vs. $1291, p-value=0.002
	• Average of all costs/month	$1534 vs. $4866, p-value<0.001
	Better hospitalisation outcomes	
	• In hospital at least once	33.7% vs. 76.1%, p-value<0.001
	• Average number of hospitalisation/month in final 30 days of life	33.7 vs. 76.1, p-value<0.001
	• Fewer hospital days/month	0.75 vs. 1.68, p-value<0.001
	• Percentage of patients admitted in hospital/month in final 30 days of life	17.4 vs. 63, p-value<0.001
	• Percentage of patients dying in the hospital	5.4 vs. 51.1, p-value<0.001
	• Average 30-day readmission rate	0.11 vs. 0.35, p-value<0.001
	• Average percentage of patients admitted in intensive care unit in final 30 days of life	8.7 vs. 34.4, p-value<0.001
	Better trends in usage in final months of life	Slight increase vs. dramatic increase
	Better cost reduction	$2690 (4.2%) vs. none
Wilson 2015	**Higher expenditures** - Based on records from JEN data management and consulting associates	**House Calls group vs. control group**
	• Percentage of patients with hospice expenditures	22.9% vs. 8.9%, p-value<0.05
	• Percentage of patients with home health expenditures	85.4% vs. 47.5%, p-value<0.05
	• Percentage of patients with social service utilization	1.4% vs. 5.5%, p-value<0.05

PATCH = Palliative Access Through Care at Home; BASE = Behaviour Analytics & Support Enhancement; MSS = Multi-Sensory Stimulation; CI-PCM = Comprehensive, Individualized, Person-Centered Management; HHS =Home Health Service; ACP = Advanced Care Planning.

Table 4. Studies mapped according to the EAPC White Paper domains.

	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10	Domain 11
	Applicability of palliative care	Person-centred care, shared-decision making	Setting care goals and ACP	Continuity of care	Prognostication, timely recognition of dying	Avoiding futile treatment[a]	Optimal symptom treatment	Psychosocial and spiritual support	Family care and involvement	Education of health care team	Societal and ethical issues
Specialist palliative care services											
Cassel 2016	✓	✓	✓	✓	✓		✓	✓	✓	✓	
Transitions											
Holley 2009		✓	✓	✓		✓	✓	✓	✓	✓	
PATCH											
Nakanishi 2018				✓			✓	✓		✓	
BASE											
Non-specialist palliative care interventions											
Baker 2001							✓			✓	
MSS											
Reisberg 2017		✓		✓			✓	✓	✓		✓
CI-PCM											
Wilson 2015		✓		✓			✓	✓			
House Calls											
Aimonino 2001							✓				
HHS											
Fabris 2004 and Tibaldi 2004			✓	✓			✓	✓	✓		
HHS											

PATCH: Palliative Access Through Care at Home; BASE: Behaviour Analytics & Support Enhancement; MSS: Multi-Sensory Stimulation; CI-PCM: Comprehensive, Individualised, Person-Centred Management; HHS: Home Health Service; ACP: advanced care planning.

[a]Avoiding overly aggressive, burdensome and futile treatment.

higher pain score was attributed to the enhanced pain assessment conducted by the trained care professionals in the intervention group, whereas the care professionals who did not receive the training course may have underestimated or remained unaware of the need for pain assessment in dementia.

Satisfaction. One of the studies (retrospective cross-sectional study of weak quality) reported outcome on satisfaction. This study suggested generally high satisfaction rate of primary caregivers of people with dementia with the care provided by the trained specialist palliative care team.[20] However, this evidence was inconclusive, as it relied exclusively on a cross-sectional survey of 22 primary caregivers of deceased people with dementia who received the intervention.

Resource use. Two of the studies (both retrospective case-control studies of weak quality) reported outcomes on resource use based on estimated costs.[19,25] Compared to usual care, the transitions programme training of specialist palliative care team resulted in lower hospital, non-hospital and all costs. It also resulted in better hospitalisation outcomes, in terms of frequency, length of stay in hospital, patient deaths in hospital, hospitalisation rates, readmission rates and admission in the intensive care unit in the final 30days of life. They also found that in the final 6 months of life, resource use in the intervention group had only increased slightly, compared with a larger increase in the control group. Net cost reduction was also better in the intervention group than the control group.[19] The other study on House Calls showed that compared to control group, patients with dementia who received medical care in their own homes were more likely to have home health and hospice expenditures, but less likely to have social health expenditures. The authors attributed the relatively low social services utilisation to the limited financial reimbursement available for social services.[25]

Facilitators and barriers to implementing the interventions

None of the studies systematically investigated facilitators and barriers to implementing the interventions. Instead, we identified information in the discussion sections of five of the studies, which could be considered facilitators and barriers to implementation.[19–21,24,27] Some intervention components may have facilitated the implementation of the interventions, including the 24-hour access to a medical practitioner[20] and the continuing provision of tailored interventions.[21] Some formal caregiver characteristics were also discussed as facilitators to implementation, such as their active engagement,[21] reliability[24] and dedicated and highly qualified teamwork.[27] The limited time allocated to implementing the interventions was considered a barrier to implementation, because it may have hindered behavioural change and the achievement of long-term effects.[19,21]

Studies mapped according to the EAPC White Paper domains

All of the interventions aimed to optimally manage symptoms at the end of life, such as pain or acute medical illnesses (Table 4). The majority of them also ensured the continuity of care by either directly facilitating the transitions of care between settings[19,20,25] or conducting multidisciplinary discussions and collaboration[21–23,27] and caregiver support meetings.[24] They also addressed the psychosocial domain by providing psychosocial support[19,20,22,23,25,27] or managing behavioural symptoms.[21,24] Four EAPC White Paper domains were rarely addressed by the interventions: applicability of palliative care, societal and ethical issues, prognostication and timely recognition of dying, and avoidance of overly aggressive, burdensome or futile treatments. In addition, 'setting care goals and advance care planning' was addressed by only three of the eight evaluated interventions.[19,20,22,23] Compared to non-specialist palliative care interventions, specialist palliative care services focused more on training the multidisciplinary healthcare team and addressed four to nine domains at once.[19–21]

Discussion

We retrieved eight studies which evaluated interventions aimed at improving end-of-life care outcomes for people with dementia living at home; three involving specialist palliative care services and five non-specialist palliative care interventions. None of the studies were of high quality, mostly due to high risk for selection bias and the inability to achieve blinding and to measure/report intervention integrity. We found weak evidence showing that home palliative care interventions in dementia can improve end-of-life care outcomes relating to institutionalisation, estimated resource use and functional status. There was moderate evidence of beneficial effects on behavioural symptoms arising from the person's cognitive and communication problems, but the evidence on whether these effects would last was contradictory. Although the evidence on pain reduction was limited and inconclusive, there was some evidence of enhanced pain assessment. Evidence on facilitators and barriers was not systematically investigated and our findings are based on limited information provided in the discussion sections of the included studies. The mapping of the studies according to the EAPC domains highlighted the main preoccupations and focus of the interventions reviewed.

The existing evidence base is insufficient and generally too weak to robustly assess the effects of home palliative

care interventions in dementia. Nonetheless, the potential benefits of the interventions in improving behavioural symptoms and enhancing pain assessment are consistent with earlier findings[13,14] and address key issues in dementia care.[28–30] Healthcare practitioners are often uncertain how to support people with dementia whose behaviours they find challenging.[31] Pain is also highly prevalent in older adults but poorly assessed in those with dementia,[30,32] which may result in patient distress and related behaviours.[33] Managing behavioural symptoms and assessing pain are not only important for patients with dementia. It may also contribute to reducing the burden of family caregivers who are central to enabling patients to stay at home.[34,35] While we know that promoting caregiver wellbeing is important,[36] it is notable that only one of the identified interventions offered additional support to address the emotional and mental needs of family caregivers.

The facilitators and barriers identified are in line with existing evidence[37,38] that highlights the importance of networks of support and easy access to tailored interventions. For example, the 24-hour access to medical practitioners and the active engagement of caregivers could enhance the accessibility of the interventions, while the tailoring of interventions based on patients' needs may increase their applicability for users.

The three most frequently addressed EAPC domains in the studies reviewed (optimal symptom management, continuity of care and psychosocial support) reflect clinician priorities and the core values of palliative care, irrespective of the reason for dying.[39] However, another EAPC priority 'person-centred care, communication and shared-decision-making' was only modestly addressed by the interventions. This is surprising when some of the most influential writing on person-centred care is situated in the dementia literature.[40] The studies failed to map according to 'applicability of palliative care' and 'societal/ethical issues' even though this is a patient population that is increasing but poorly understood by commissioners and policymakers and stigmatised in society.[41] Other domains that were under-represented in the evidence reviewed: prognostication and timely recognition of dying, avoidance of overly aggressive, burdensome or futile treatments and setting of care goals and advance care planning are similarly problematic areas in dementia care. For instance, despite the fact that most older people prefer to die at home,[7] there may still be a substantial proportion of older people with dementia dying in hospitals,[30] which is likely to occur if the palliative phase is not promptly recognised. Also, progressive cognitive decline is inherent in advanced dementia, which hinders the communication between healthcare providers and people with dementia.[1]

Implications for research and practice

The lack of evidence suggests that palliative care interventions have been given a low priority in dementia care, particularly in the home setting.[12] This may also be because most of the evidence on palliative care interventions for people with dementia is still situated in the nursing home setting,[12] where in many countries, the majority of people with dementia spend their final months or years of life.[42] Findings from the mapping of the studies according to the EAPC domains raised a question about whether research to date had given adequate attention to the specific issues and challenges experienced by people with dementia. It also highlighted the problems of transferring learnings about symptom management, continuity of care and psychosocial support from one specialty (e.g. cancer care) to the experience of dying with and from dementia. Symptom management should always be a main priority. However, the EAPC domains where there are gaps, are the domains that are very particular to the experiences of living and dying with dementia. Dementia is a socially stigmatised condition, with a highly variable and protracted dying trajectory and one where decisions to treat and/or avoid burdensome treatments involve multiple stakeholders.[43,44] The review thus demonstrates that it may still be the early days in research for people with dementia living and dying at home. High-quality dementia-specific research is therefore required to further support the evidence base for palliative care interventions to be a routine care for people with dementia living and dying at home.[10] In designing such palliative care interventions, it is crucial to also consider strategies that would address the specific needs of home-dwelling people dying with and from dementia, for example, prognostication of dying, avoidance of overly aggressive treatments or advance care planning, as well as interventions to assess and address the individual needs of family caregivers.

This systematic review also highlights a number of gaps in the evidence. We found a lack of consensus on the outcomes used, which limited comparisons and meta-analysis. Important end-of-life care outcomes, for example,. patient death at home and quality of life were also not consistently measured.[7,39] These issues around outcome measures may be addressed by two ongoing studies aiming to develop standard core outcome sets in dementia, one of which focuses on the home setting, while the other study involves people with dementia in research.[45,46] Although the core outcome sets to be developed can be relevant and applicable for people with dementia, it is still important to further explore the extent to which these outcomes would be relevant and applicable in evaluating home palliative care interventions in dementia. Guidelines on how to develop such core outcome sets exist, such as the handbook developed by the Core Outcome Measures in Effectiveness Trials (COMET) initiative. The COMET initiative aims to guide the development of core outcome sets by bringing together relevant key stakeholders, including patients.[47] Most of the studies were also appraised to have weak quality in part due to their inability to measure/report

intervention integrity. This has been found as a persistent issue in clinical trials in palliative care,[48] which could be addressed by using standard reporting tools, for example, CONSORT statement.[49] Evidence on cost-effectiveness is also scarce. While some studies reported resource use, it was solely based on estimated costs while disregarding health benefits. Performing concurrent cost-effectiveness analysis using existing guidance could provide a better view of interventions that could potentially yield the greatest improvement in dementia care for the least resources.[50] Finally, evidence on facilitators and barriers was limited. This could be addressed by undertaking process evaluation, which is increasingly being recognised as an integral part of designing and evaluating complex interventions such as palliative care interventions. Performing process evaluations in accordance with the Medical Research Council (MRC) guidance would allow the critical exploration of factors and causal mechanisms that could explain variations in observed outcomes.[51]

Strengths and limitations

We systematically and rigorously searched the literature for existing studies on home palliative care interventions in dementia. It was a strength of the study that we drew on the EAPC White Paper to structure the data extraction and analysis. This demonstrated how the evidence was distributed according to an international consensus on what should be the key activities and focus of palliative care in dementia. However, we only found eight relevant studies, none of which were of high quality. The evidence of effectiveness therefore needs to be interpreted with caution. We adopted a broad definition of non-specialist palliative care interventions which may mean that relevant studies were missed. However, our searches were systematic and electronic database searching was supplemented with lateral searching. Our decision to only include quantitative studies, and associated process evaluations, may explain the limited evidence on facilitators and barriers to implementation. However, forward citation tracking of the included studies also did not reveal any relevant studies. To better identify studies that could yield valuable information on factors influencing the implementation of home palliative care interventions in dementia, future reviews should consider the inclusion of both qualitative and quantitative studies. We would also recommend a regular update of the systematic review, as new scientific evidence on factors influencing the implementation of home palliative care interventions emerges, such as the follow-up study of Nakanishi et al.[52] Finally, subjectivity may have been introduced in the mapping of the intervention components according to the EAPC White Paper domains. We dealt with this challenge by discussion within the research team.

Conclusion

The review offers evidence on palliative care interventions for people with dementia living at home and highlights the paucity of high-quality studies in this area. The review emphasises the need for more rigorous and comprehensive research which considers the identified gaps in the evidence and addresses the specific issues and challenges that dying at home with or from dementia poses. The EAPC's definition of optimal palliative care in dementia provided a useful framework for a systematic assessment of the range and focus of evidence of what is effective for people with dementia living and dying at home.

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References

1. Lunney JR, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA* 2003; 289(18): 2387–2392.
2. Van Der Steen JT. Dying with dementia: what we know after more than a decade of research. *J Alzheimers Dis* 2010; 22(1): 37–55.
3. Prince M, Comas-Herrera A, Knapp M, et al. *World Alzheimer report 2016 improving healthcare for people living with dementia: coverage, quality and costs now and in the future*. London: Alzheimer's Disease International, 2016, pp. 1–140.
4. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 7.
5. Ewbank L, Thompson J and McKenna H. NHS hospital bed numbers: past, present, future, 2017, https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers

6. Samus QM, Black BS, Bovenkamp D, et al. Home is where the future is: the BrightFocus Foundation consensus panel on dementia care. *Alzheimers Dement* 2018; 14(1): 104–114.
7. Fox S, FitzGerald C, Harrison Dening K, et al. Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. *BMC Palliat Care* 2017; 17(1): 9.
8. Sampson EL. Palliative care for people with dementia. *Br Med Bull* 2010; 96(1): 159–174.
9. Hughes JC. Promoting palliative care in dementia. *Lancet Neurol* 2010; 9(1): 25–27.
10. Van den Block L. The need for integrating palliative care in ageing and dementia policies. *Eur J Public Health* 2014; 24(5): 705–706.
11. Van Der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014; 28(3): 197–209.
12. Murphy E, Froggatt K, Connolly S, et al. Palliative care interventions in advanced dementia. *Cochrane Database Syst Rev* 2016; 12: CD011513.
13. Singer AE, Goebel JR, Kim YS, et al. Populations and interventions for palliative and end-of-life care: a systematic review. *J Palliat Med* 2016; 19(9): 995–1008.
14. Gomes B, Calanzani N, Curiale V, et al. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Libr* 2013(6): 93–94.
15. Joint Programme – Neurodegenerative Disease Research. Palliative and end-of-life care research in neurodegenerative diseases. A report of the JPND Action Group, 2017, http://www.neurodegenerationresearch.eu/tag/action-group-report/
16. OECD. Care needed: improving the lives of people with dementia. In series: OECD Health Policy Studies. Paris, 2018, https://read.oecd-ilibrary.org/social-issues-migration-health/care-needed_9789264085107-en#page1
17. Hum AY, Wu HY, Ali NB, et al. The dignity in advanced dementia (diadem) study: developing an integrated geriatric palliative homecare program. *Prog Palliat Care* 2018; 26(2): 1–8.
18. Effective Public Health Practice Project. *Quality assessment tool for quantitative studies*. Hamilton, ON, Canada: Effective Public Health Practice Project, 1998, https://merst.ca/ephpp/
19. Brian Cassel J, Kerr KM, McClish DK, et al. Cassel 2016: effect of a home-based palliative care program on healthcare use and costs. *J Am Geriatr Soc* 2016; 64(11): 2288–2295.
20. Holley APH, Gorawara-Bhat R and Dale W. Holley 2009: palliative access through care at home: experiences with an Urban, geriatric home palliative care program. *J Am Geriatr Soc* 2009; 57(10): 1925–1931.
21. Nakanishi M, Endo K, Hirooka K, et al. Psychosocial behaviour management programme for home-dwelling people with dementia: a cluster-randomized controlled trial. *Int J Geriatr Psychiatry* 2018; 33(3): 495–503.
22. Fabris F, Molaschi M, Aimonino N, et al. Home care for demented subjects: new models of care and home-care allowance. *Arch Gerontol Geriatr Suppl* 2004; 38(Suppl. 9): 155–162.
23. Tibaldi V, Aimonino N, Ponzetto M, et al. A randomized controlled trial of a home hospital intervention for frail elderly demented patients: behavioral disturbances and caregiver's stress. *Arch Gerontol Geriatr Suppl* 2004; 38(Suppl. 9): 431–436.
24. Reisberg B, Shao Y, Golomb J, et al. Comprehensive, individualized, person-centered management of community-residing persons with moderate-to-severe Alzheimer disease: a randomized controlled trial. *Dement Geriatr Cogn Disord* 2017; 43(1–2): 100–117.
25. Wilson K and Bachman SS. House calls: the impact of home-based care for older adults with Alzheimer's and dementia. *Soc Work Health Care* 2015; 54(6): 547–558.
26. Baker R, Bell S, Baker E, et al. A randomized controlled trial of the effects of Multi-Sensory Stimulation (MSS) for people with dementia. *Br J Clin Psychol* 2001; 40(Pt. 1): 81–96.
27. Aimonino N, Molaschi M, Salerno D, et al. The home hospitalization of frail elderly patients with advanced dementia. *Arch Gerontol Geriatr Suppl* 2001; 7: 19–23.
28. Penders YWH, Albers G, Deliens L, et al. End-of-life care for people dying with dementia in general practice in Belgium, Italy and Spain: a cross-sectional, retrospective study. *Geriatr Gerontol Int* 2017; 17(10): 1667–1676.
29. Meeussen K, Van den Block L, Echteld M, et al. Older people dying with dementia: a nationwide study. *Int Psychogeriatr* 2012; 24(10): 1581–1591.
30. Miranda R, Penders YWH, Smets T, et al. Quality of primary palliative care for older people with mild and severe dementia: an international mortality follow-back study using quality indicators. *Age Ageing* 2018; 47(6): 824–833.
31. Trivedi DP, Braun A, Dickinson A, et al. Managing behavioural and psychological symptoms in community dwelling older people with dementia: 1. Dementia (London). *Epub ahead of print* 1 January 2018. DOI: 10.1177/1471301218762851.
32. Corbett A, Husebo B, Malcangio M, et al. Assessment and treatment of pain in people with dementia. *Nat Rev Neurol* 2012; 8(5): 264–274.
33. Malara A, De Biase GA, Bettarini F, et al. Pain assessment in elderly with behavioral and psychological symptoms of dementia. *J Alzheimers Dis* 2016; 50(4): 1217–1225.
34. Eska K, Graessel E, Donath C, et al. Predictors of institutionalization of dementia patients in mild and moderate stages: a 4-year prospective analysis. *Dement Geriatr Cogn Dis Extra* 2013; 3(1): 426–445.
35. Luppa M, Luck T, Brahler E, et al. Prediction of institutionalisation in dementia: a systematic review. *Dement Geriatr Cogn Disord* 2008; 26(1): 65–78.
36. Mittelman MS, Haley WE, Clay OJ, et al. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology* 2006; 67(9): 1592–1599.
37. Mogan C, Lloyd-Williams M, HarrisonDening K, et al. The facilitators and challenges of dying at home with dementia: a narrative synthesis. *Palliat Med* 2018; 32(6): 1042–1054.
38. Erel M, Marcus E-L and Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: a scoping review. *Ann Palliat Med* 2017; 6(4): 365–379.
39. World Health Organization (WHO). WHO definition of palliative care, http://www.who.int/cancer/palliative/definition/en/
40. Edvardsson D, Winblad B and Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol* 2008; 7(4): 362–367.

41. Batsch NL and Mittelman MS. World Alzheimer report 2012: overcoming the stigma of dementia. *Alzheimer's Dis Int* 2012: 1–80.
42. Mitchell SL, Teno JM, Miller SC, et al. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc* 2005; 53(2): 299–305.
43. Dempsey L, Dowling M, Larkin P, et al. The unmet palliative care needs of those dying with dementia. *Int J Palliat Nurs* 2015; 21(3): 126–133.
44. Paque K, Vander Stichele R, Elseviers M, et al. Barriers and enablers to deprescribing in people with a life-limiting disease: a systematic review. *Palliat Med* 2019; 33: 37–48.
45. Harding AJE, Morbey H, Ahmed F, et al. Developing a core outcome set for people living with dementia at home in their neighbourhoods and communities: study protocol for use in the evaluation of non-pharmacological community-based health and social care interventions. *Trials* 2018; 19(1): 247.
46. Morbey H, Harding AJE, Swarbrick C, et al. Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. *Trials* 2019; 20(1): 12–10.
47. COMET initiative, 2019, http://www.comet-initiative.org/
48. Bouca-Machado R, Rosario M, Alarcao J, et al. Clinical trials in palliative care: a systematic review of their methodological characteristics and of the quality of their reporting. *BMC Palliat Care* 2017; 16(1): 10–12.
49. Piggott M, McGee H and Feuer D. Has CONSORT improved the reporting of randomized controlled trials in the palliative care literature? A systematic review. *Palliat Med* 2004; 18(1): 32–38.
50. World Health Organization (WHO). *Making choices in health: WHO guide to cost-effectiveness analysis* (Glob Program Evid Heal Policy). Geneva: WHO, 2003, p. 71. http://www.who.int/choice/publications/p_2003_generalised_cea.pdf
51. Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: Medical Research Council guidance. *BMJ* 2015; 350: h1258.
52. Nakanishi M, Hirooka K, Imai Y, et al. Dementia care competence among care professionals and reduced challenging behavior of home-dwelling persons with dementia: a pre- and post-intervention data analysis. *J Alzheimers Dis* 2018; 64(2): 515–523.